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Abstract

DIGITAL SUPPORT FOR SELF-MANAGEMENT AND HEALTH LITERACY IN PARKINSON'S DISEASE

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Background

Patients with Parkinson's disease (PD) require a substantial amount of self-management (SM) and health literacy (HL) skills to actively manage their health and engage efficiently with healthcare professionals (HCP). Low level of HL can negatively affect health outcomes, and many PD patients face challenges in increasing their HL skills. We are developing on a novel digital tool- electronic diary (eDiary) to empower PD patients by improving low HL and enabling self-management within their multidisciplinary healthcare team. Successful eDiary development requires active engagement of patients and informal caregivers to identify their needs, expectations and challenges for using eDiary app. The requirements of HCPs are also collected to align with current care practices and challenges of digitally supported patient management and communication.

Objective

To evaluate the expectations and challenges from patients, informal caregivers and HCPs towards the eDiary app and how it can support SM and HL.

Methods

Mixed methods co-design study is composed of 3 parts: **survey** (aim to evaluate current status of SM and HL), **individual interviews** (aim to identify current SM and HL challenges and needs for support), **focus groups** (aim to co-design eDiary app in 4 stages: content, user interfaces, user journeys and data visualization).

Preliminary findings and next steps:

First results from focus group with HCPs provided the care service requirements for eDiary that will be extended with patients and caregivers. Involvement of multiple end-users is essential to gather a variety of perspectives and ensure comprehensive representation of SM and HL domains. After technical implementation of eDiary a clinical validation study will evaluate if eDiary usage increases SM, HL skills and health outcomes.